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IMPAIRED VISION AND BLINDNESS:
THE PREVENTION OF DISABILITY, SOCIAL ISOLATION,
AND UNTIMELY DEATH

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For
CLEVELAND HEALTH GOALS PROJECT

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Cleveland, Ohio

NOTE REGARDING POSITION PAPERS

This is one of about thirty papers being prepared for the Cleveland Health Goals Project. In the process of determining health goals for the Greater Cleveland Area, the Project Committee will be greatly assisted by these papers but will not necessarily incorporate all of the suggestions advanced by the authors. Thus each paper can be viewed as the "position" of its author but not, in this form, as the position of the Project.

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THE PREVENTION OF SOCIAL OSTRACISM AND DISABILITY RESULTING FROM BLINDNESS OR VISUAL HANDICAP

I. INTRODUCTION

This position paper is sadly lacking in statistics. The author has little faith in most of the existing statistical information regarding blindness and seriously questions the present and generally accepted definition of blindness.

For purposes of the paper the author has divided the visually handicapped into two groups which he refers to as the "truly blind" and the cecutient. In the paper itself, the author's definitions of these terms are given but they are admittedly vague. The paper notes that the truly blind would probably be considered those having less vision than 3/200 or at most 5/200. He makes use of the term "cecutient" for the whole range of vision from this 3/200 or 5/200 area up to nearly normal vision.

Although it is not possible to give actual statistical information, some broad lines of probability have been opened up by an excellent pilot study of visual impairment made recently in the Cleveland area by the American Foundation for the Blind with support from the National Institute of Neurological Diseases and Blindness and the Cleveland Foundation. The author of this position paper feels it imperative that anyone using the paper should supplement it with a study of the report or at least the

abstract resulting from that pilot study. It might also be hoped that Dr. Eric Josephson, principal investigator for the study, could be called upon to discuss this position paper and to make such statistical projections as he might see fit.

The National Health Survey done by the Public Health Service would indicate an incidence of "severe visual impairment" of 19.3 per thousand in the Cleveland area. The AFB pilot study referred to found an incidence of 23.8 per thousand. The author has no factual information but inclines toward the AFB figure. Both studies would indicate that the "legally blind" in the Cleveland area would be 2 per thousand.

The pilot study sample is probably too small for any estimate as to the numbers in any given age group or for that matter to have any degree of reliability with regard to additional handicaps. Nor is it sufficiently clear to be of assistance when it comes to vision between 5/200 and nil. The author of this position paper would, therefore, make the best "guess-timate" that the number of what he refers to as the "truly blind" in the greater Cleveland population would be 1 per thousand; the number of those legally blind but not "truly blind", 1 per thousand; and the number of "cecutient", perhaps 20 per thousand. These figures are put forward hesitantly and with apologies but it seems impossible to arrive at better ones at the present time.

Since it is possible that, in evaluating this position paper and in further steps in planning for the Greater Cleveland

area, reviewers unacquainted with work for the blind will be discussing visual handicaps and blindness with many persons from that field, the author of this paper presumed to include in this introduction a somewhat unusual "glossary of terms" entitled "The Semantic Trap". This is included as a caveat so that the uninitiated may not be confused by terminology which means one thing to one expert and something else to another. Unfortunately, the field of typhology (a little used but valid term meaning the science and art of dealing with blindness) has not been able to find standard terms which always communicate the same meaning.

It is possible that within the position paper the reviewer will find something of the same haziness with regard to terminology.

The author of this paper would further state at this point that fortunately the field of work with the blind is not a monolithic one and that the philosophy and viewpoints in this paper are not necessarily shared by all workers for the blind.

THE SEMANTIC TRAP

A Glossary of Nonmedical Terms

- Cecutiency
1. The state of partial sightedness or near blindness without reference to prognosis.
 2. The same state with the implication that blindness is increasing, i.e., sight is diminishing.

- Cecutient
1. Partially sighted.
 2. Partially sighted and losing vision.

Partially Sighted

1. Legally blind.
2. Having some vision but less than 5/200 in the better eye.
3. Having some vision but less than 20/200 in the better eye.
4. Having some vision but less than 20/70 in the better eye.
5. Vision between 20/70 and 20/200, not including any vision under 20/200.
6. Etc.
7. Sometimes used by ill-informed for those with good monocular vision with no sight in the other eye.

Partially Blind

A term used by persons not in the field, rarely by those active in the field, as reference to any degree of loss of sight.

Legally Blind

1. The state of being "blind" within a definition established by law, in most parts of the country stated in such terms as "having vision of 20/200 in the better eye with correction or having an equivalent restriction of field."
2. In other countries: either
 - A. The same as the United States.
 - B. Vision 5/200 or less.
 - C. Total blindness.

Sand-Blind

(rarely used) Partially blind, half blind, as if specks of sand or other particles were blurring the vision.

High-gravel Blind

(Shakespearean cf. Merchant of Venice), more than half blind.

Stone-Blind

(frowned upon by workers for the blind), meaning totally blind.

Purblind

1. Formerly totally blind (a composition resulting from pure and blind -- pur being an intensive prefix.)
2. Nowadays near-sightedness or dimness of vision.

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|----------------------------|---|
| <u>Amaurotic</u> | <ol style="list-style-type: none">1. Blind.2. Purblind.3. Sight decay without apparent organic cause. |
| <u>Cecity</u> | (seldom used) Blindness. |
| <u>Obfuscated</u> | (rare) Partially blind, partially sighted, nearsighted. |
| <u>Industrially Blind</u> | <ol style="list-style-type: none">1. Having less than 20/50 vision.2. Having less than 20/70 vision. |
| <u>Educationally Blind</u> | <ol style="list-style-type: none">1. Having less than 20/70 vision.2. Having vision in sufficient degree to read ordinary print.3. Having vision so poor that braille is a necessary vehicle for learning. |
| <u>Monocular</u> | <ol style="list-style-type: none">1. Having vision in one eye only.2. Making use of only one eye although some vision is possible with the other. |
| <u>Sighted</u> | <ol style="list-style-type: none">1. Having such good vision that eyeglasses are never needed, "normal vision"; (20/20 or better).2. Having vision within a "broad normal range", better than 20/200.3. As opposed to 20/200, having any degree of vision including partial sightedness or perfect sight. |
| <u>Nearly Blind</u> | <ol style="list-style-type: none">1. Any degree of partial sightedness with no reference to prognosis.2. Any degree of partial sightedness with likelihood of further and complete loss of sight. |
| <u>Blind</u> | <ol style="list-style-type: none">1. Total and complete absence of vision. (Seldom so used by workers for the blind.)2. The state of visual loss anywhere from 20/50 to total blindness. |
| <u>Totally Blind</u> | <ol style="list-style-type: none">1. Just that -- totally blind.2. (V.A. definition) -- either totally blind or having vision amounting to less than 5/200. |

II. DISCUSSION

A. THE TOTALLY BLIND

We perhaps might entitle this the "Truly Blind". Included in this group will be all those so handicapped that their sight is not useful. This would certainly include those without eyes. It would also include those with light perception or light projection. It is questionable what the limit would be beyond that, but the probability is that it would reach somewhere near 3/200 vision or 5/200 vision.

We will later treat the cecutient in a separate section.

1. The Child Born Blind

The percentage of infant blindness in the general population has been decreasing since the early part of this century. (There was a time when retrolental fibroplasia greatly increased the percentage, but this has been practically wiped out as a cause.) Yet the numbers of those born blind are increasing in our country as the number of births increases. Additionally, there is some reason to believe that other factors are at work at least in the area of amaurosis exanopsia.

Whatever the numbers, the problem of the child born blind is major. It is a problem involving his parents and his siblings and work must be done with both.

In his early years it is especially important that the child born blind be encouraged to inquisitiveness, exploration and daring -- and yet it is also important that the environment

which he explores must be to a degree fixed. All of this is strange to the parent. Additionally, parents have difficulty with regard to questions of heredity and questions of their own ability as men and women to reproduce.

This then is a time of disturbance and difficulty for parents. It is essential that work for the blind offer home consultation in a number of ways. The social worker with an understanding of the psychological dynamics at work in the family is necessary. Home consultation must include also proper training of those persons important to the family -- clergy, physicians, older members of the family, grandparents, in-laws, etc., and all those having some status position with regard to the parents.

Home consultation must include, however, something more. It must include a knowledgeable person who can bring to the family the importance of what we have described as inquisitiveness, exploration and daring, and also the matter of the fixed immediate environment. Thus some expertise in the area of blindness and children is demanded.

This expertise may well be found in a home consultant who is primarily oriented as a teacher. Either in this same teaching expertise or elsewhere must be found ability to help the child to develop recreationally.

Beyond this the future will see a developing work of mobility with pre-school children. At this point our knowledge is not sufficiently great for us really to understand how to

teach mobility and orientation to the pre-school child. However, the demands of the program will bring research into this area. In consequence I would predict that within ten years we will be doing some mobility training or at least orientation training for the pre-school child. This will demand further expert personnel.

In the pre-school years it is probably necessary that the parents of blind children have some group experience. In the past this has come primarily from parents' groups seeking better service for their children. Since the height of retrolental fibroplasia these groups have diminished in strength and importance. It is now necessary that social agencies, private or public, encourage the formation of groups and that they bring to these groups a psychological competence which allows for therapy from them.

Still working with the pre-school child, we recommend the availability of the psychiatric consultation, (a) for parents of blind children, (b) for children themselves where indicated, and (c) in a consultative way for workers with the pre-school child. Lest this last seem a luxury, it should be pointed out that work with a trauma as serious as blindness, and especially working with such a trauma in children, has a potential for mobilizing any neurotic traits in the worker. It is therefore especially important that the pre-school worker have access to a psychiatric interpretation.

There is no knowledge as to the amount of brain damage found in pre-school blind children, but experience teaches us that at least some children are so damaged -- whether the blindness results from a brain injury, or whether the brain damage and blindness result from the same cause. In instances where these two disabilities occur together, there is no special program known to us. It is recommended that the worker be sufficiently oriented professionally so as to work with consultants familiar with brain damage. The same is true with mental retardation, cerebral palsy, and other disabilities.

Deafness in the blind child or any profound hearing loss calls for special consideration. It is highly recommended that every blind child receive a complete audiological examination and see an otologist where indicated.

a. Nursery School and Kindergarten

By the time that nursery school age is reached, the agency must have some sort of educational consultant available to the parents and also to the nursery school. It is highly recommended that the normal blind child attend nursery school with normal sighted children, but it is necessary that the nursery school personnel should have consultation so that they will understand the special problems of the blind child and assist in a special way with integration of the child. Ordinarily sighted children at this age are interested in the blind child and without innate prejudice. At times the teacher will begin to instill prejudice without realizing it, and the blind child

will become either the pet of the class or the one set aside and not allowed to take part in normal activities.

Here again the need is great, indeed urgent, for inquisitiveness, exploration and daring.

In these years it may be that physical therapy and occupational therapy can be called upon to assist in the development of the child, particularly in developing his motor skills, his poise, and posture.

Above all, in the future it will be important that the peripatologist be involved at this period of development. (At this writing we still know too little to expect the peripatologist to be expert with these children, but his training should be such that he can develop poise, posture and the beginnings of mobility.)

What we said above about the brain-damaged, retarded, cerebral-palsied or otherwise handicapped child remains true. Those working with the blind child must be adept at consulting with others and working with them to develop individualized imaginative plans.

Here again hearing loss looms very large and regular otological and audiological examinations are called for with consultation on medical aspects being immediate when indicated.

2. The Child Losing Sight from Birth to Five Years of Age

It must be recognized that in many ways these children are considered as "congenitally blind". The fact is that many

of them upon losing sight move through the same stages of shock and depression as does the adult. If not this, then many of them move through equivalent stages. The loss of contact with the reality environment through sight and the loss of confidence in their remaining senses have been seen to drive some of these children into states of mental upset and disturbance. Here then especially expert consultation must be at hand. This consultation must serve the ophthalmologist, the family physician, parents, and the whole environmental group.

3. The Blind Child in Grammar School

The normal blind child should have every opportunity for schooling in the local school system -- in the same schools that his siblings attend or would attend. For this purpose the community must furnish itinerant teachers moving from school area to school area, teaching the child those things that the ordinary teacher cannot give him, which have to do with his blindness.

In some instances the education of the blind child will make use of a "resource room" or "resource teacher" in his own local school. Occasionally this must be called for but there seems sufficient reason now to believe that the capable itinerant teacher working with a small case load can handle the problem sufficiently well.

At the same time recognition must be taken of the fact that certain children cannot be taken care of in the local schools. Because of this, access to the segregated school (the residential school for blind children) must be available.

Because of diverse parental drives in this matter, and because of differing opportunities at home, it becomes important that the community furnish consultation to the parents to assist in determining whether the child should go to a local school or to the segregated residential school. This area is a complex one but it should not be left to parents to make the determination without assistance.

If the child goes to the local school, recreational opportunities must be provided. In general the itinerant teacher will be in the position to make sure that this is done. Yet the community must be assured that opportunities for physical education, for physical sports, as well as hobby activities, will be provided.

Above all, whether in the local school or in the residential school, from grammar school days on, the peripatologist must be called upon to work closely with the child developing his environmental knowledge and his mobility skills.

Here again we stress the need for daring, exploration and the opportunity for self-development. It is difficult enough for the sighted child wrapped in cotton; it becomes especially difficult for the blind child so hindered to reach his full

development.

In grammar school days enrichment opportunities of all kinds must be provided. For this purpose, opportunities for special counseling are essential -- a special counseling which involves not only the blind child but again the parent, the sibling, and the whole familial environment.

Until now little has been done with regard to vocational training at this level. It is strongly recommended that opportunities be provided for the beginnings of exploration in this area, and that counselors, itinerant teachers and other professionals dealing with the child constantly evaluate and re-evaluate the ability of the child and the desires which are developing in him.

Vacation time is important for the child in grammar school -- whether he attend the local school or the segregated, residential school. It is in the vacation period that many blind children lose the degree of integration which they obtain during the school year. Not only is directed and supervised recreation important but it is necessary that the blind child have the same access as other children to non-supervised recreation, the opportunity for play without adult interference.

We cannot overlook the brain-damaged, the retarded, the cerebral-palsied or the others in this period of life. Now it becomes important more than ever that consultation take place so that these doubly-handicapped children may have the necessary assistance to take part in activities for their develop-

ment and future growth.

As for deafness at this stage of development, it now seems necessary that the profoundly deaf, totally blind child be at one of the special centers of which there are few in the country, where he can receive that training which is demanded by his two-fold disability. It is hoped that in future years more of these children can be trained in a local environment and saved from the uprooting which our present system demands.

The child losing sight during these years -- whether he had had poor sight from birth or whether something caused the sudden loss of his good sight -- demands special help. Nothing exists in the way of a rehabilitation center for such children. It, therefore, becomes necessary that (a) special counselors be deeply involved in his life, or (b) he be sent to a residential school for at least a period of a year. It is our opinion that the latter is extremely traumatic. We would recommend it only as a last resort. Instead we would call on psychological consultants, peripatologists, and home teachers to work closely with the parents as well as with the child in developing his skills and returning him to his local school.

4. The Blind Child of High School Years

In high school again the choice is between the local school system or the residential school for the blind. Our own bias is strongly in favor of the local high school system.

The child brought up from birth as blind, having come up through regular kindergarten and grammar school, should be socially prepared and educationally prepared to enter his local school.

At this point it becomes difficult to choose the courses for him. The tendency is strong to choose those courses which are only intellectual in nature -- thus causing difficulties for the child who is less than bright-normal or in some instances for the bright-normal child.

Further exploration must be made with regard to trade school courses, and of course encouragement must be given for classes in business schools. This area is difficult in this stage of United States education because for the most part our trade schools are so badly outmoded. As we turn towards a development of the so-called trade school, the problems of blind children must be brought into focus.

At high school the already existing needs of reader service become urgent. The community must be in a position to furnish readers to the blind child in a way which will not make him dependent upon his fellows or demanding of them. This is best done by an appropriation allowing the state to pay for proper reader service.

Additionally there must be services whereby textbooks are brailled or taped. Such a service existing locally must be coordinated with national library service so that there will not be unnecessary duplication of textbooks and that

textbooks brailled locally may be available to blind children in other areas of the country.

In high school years recreation again assumes an importance. Whatever consultation is available for the blind child from educational services or social agencies must be aware of this importance and must give the child again the opportunity for daring participation in physical sport and in general for that physical development which is necessary. Here the consultant (perhaps the peripatologist) will be especially watchful for the correction of any blindisms which may have developed or for the avoidance of those blindisms which may be developing.

Recreation at the high school age must not be confined to the merely physical; it must include all aspects of social recreation. And now the blind child needs expert assistance with regard to his sexual maturation and his normal meeting with members of the other sex and the same sex. Here the highest skill is demanded of the counselor, and once again the parents and the familial environment must be involved.

In high school mobility skills and orientation are an absolute necessity. The peripatologist must see to it that the child has an opportunity to move wherever he will with grace, ease and relative safety.

Although the changes in American society have decreased the number or percentage of high school students who can earn and take responsibility financially, it nevertheless

still remains that this is a factor of life for many sighted high school students, and everything must be done to develop equal or similar opportunities for blind high school students.

Dropouts become a consideration at this period. For the most part the dropouts among blind children will be among those with added physical disabilities or those who have not the mental capacity to keep up with the course whatever it may be. We begin then to touch on the question of employment for those marginal young persons and of financial security for them lest they be or feel themselves to be an unwanted burden for their parents.

For young people dropping out of school, rehabilitation counseling becomes important and an attempt at job placement of some kind or other. Here too comes the question of financial assistance. We will take this up more thoroughly in a later section, but we suggest that it becomes important even in these years.

Rehabilitation counseling must not be left, however, for those who are dropping out of school. From the earliest high school years, counseling and specifically job counseling becomes important to direct the future of these young people.

As for those losing sight in this age group -- whether they were always of poor vision or whether their good vision was suddenly lost -- it is our strong opinion that the immature among them will best be treated as those of grammar

school age mentioned above, but the mature among them should turn to the rehabilitation center for blinded adults and there receive a course of training which will fit them to return to their high school courses.

5. Post-High School Years

The first treatment here must concern the child who has completed high school and who is not ready to go on to college.

Recognition must be made of the fact that he is suddenly thrown into competition in a sighted world, and the meeting of this competition may call for a degree of counseling not needed by the sighted high school graduate.

Rehabilitation counseling will concern itself primarily with job opportunities for the blind young person. This demands a degree of imagination which will keep the student from being placed in a stereotyped blind job. Beyond this it demands a degree of continuing counseling which will enable him to have a choice of employment in the future -- whether moving up in his present employment or moving across to another position where advancement will be possible.

Counseling for this group must not stop with job counseling. Even for the child who has gone through integrated schools, some social counseling is necessary at this time. Particularly for the child who has been in the sheltered blind environment of the segregated school, special counseling

is demanded. At times this may take place in a group context.

If the young person has moved up through the various modes of education which we have counseled, his mobility should not be a major factor at this time. The community must, however, be alert to the fact that many children will have been denied this opportunity and that consequently some blind persons at this age will be immobilized and helpless. Here again the competence of the peripatologist is called for.

College, while presenting a special opportunity, presents special problems as well. College education has recently been more readily available to blind students than to the general run of sighted students -- partly because much of their education has been conceptual, and partly because the community has seen fit to furnish scholarship aid to blind students in greater degree. Although college education presents special opportunities, it should be entered into by a blind student only with that kind of counseling which shows its drawbacks as well. (Our special fixation has to do with the "noblesse oblige" concept of college education which will not allow the blind student to take a blue-collar job after graduation without feeling guilty about it.)

At the college level, reader service, taping service, and braille textbook service are of extreme importance. At the same time, consultation must be given by educational experts in the field of blindness as to how best to make use of these and other devices for obtaining a full and complete education.

Counseling and guidance with regard to career again is demanded.

As for those losing sight in the years after high school -- whatever the cause and whatever the background -- there must be available, whether within the small community or a large geographical region, the most expert type of rehabilitation center.

We strongly believe that such a center must not be a workshop; it must not be workshop oriented; it must not commingle those losing their sight as adults with those who have always been blind; and it must make use of many different professional disciplines to restore to the blinded person all those things which his blindness has cost him.

As for recreation in these years, every attempt must be made to steer the blinded person away from segregated or group recreation in order to give him the broadest experience.

I note the need for regular audiological examination and otological consultation.

6. The Adult Blind or Blinded

For many of the persons we have talked about, adult years should demand no special service by agencies for the blind. If they have been successful in achieving their educational goals and employment goals and have become socially a part of a sighted world, then it can be presumed that they will need no services from agencies for the blind in many cases.

There still will be available to them such special national services as are given by the Library of Congress and others with regard to reading, whether in braille, on the talking book, or by tape, and national consultation will be available in the rare instances where special devices are demanded for their employment or their living convenience.

Idealism, however, can be carried to extremes. Realism says that many of the persons who have come through as blind from early childhood will not have made this goal.

A major factor in their disability will be the attitude of the sighted community. No greater service can be given by an agency for the blind than the constant education of this sighted community. The ideal community would tackle this by working against prejudice. It would set up for blind and otherwise handicapped persons anti-prejudice groups and public relations groups whose background might be similar to that of B'nai B'rith's Anti-Defamation League, rooting out prejudice against the disabled wherever it is found.

Beyond this, job counseling and job placement service is of the greatest need. This service works to overcome the prejudices of employers and to open up opportunities for employment to those who are blind. The opportunity for employment is important; almost equally important is the opportunity for advancement, or the opportunity to change freely to a new position. Our concern would be that the service not merely place blind persons but assist them in getting on

to better opportunities or freedom of employment choice.

As for the truly marginal, it may be necessary that there be workshops -- sheltered shops of some variety. It is urgent that such shops make rules restricting themselves only to the marginal -- blind persons who are physically marginal or mentally or emotionally marginal. The great tragedy of sheltered shop programs in the history of blindness has been that they take blind persons who are other than marginal, destroy their independence and their motivation and thus make them marginal or sub-marginal for life.

While speaking of workshops, we would insist that any intelligent community not use a workshop situation for so-called rehabilitation training. All too often these shops whose supposed purpose is rehabilitation lead only to the motivation of sheltered employment.

Financial security is essential for any blind person who would go on to better opportunities. Without financial security, a degree of anxiety is aroused which interferes with his rehabilitation training and his job seeking. All laws, therefore, which have to do with financial aid to needy blind persons should be reviewed to see that they offer a substantial floor of financial security so that the blind person will not be made neurotic by worries about his ability to live in some degree of ease and lack of worry.

Not only are there some whose other disabilities have kept them from "making the grade". There are others

who have come to this state in life blind and capable but who suddenly acquire some added disability which interferes with their adjustment. Here again the community must be prepared to give proper consultation so that experts in the field of the secondary disability may have access to the knowledge of experts in the field of that which is primary.

Deafness or profound hearing loss is so severe for a blind person that communities should make sure that blind persons have some regular audiological examination and that otological consultation is available at all times.

Many blind persons are concerned over the possibility of hereditary factors with regard to their blindness. Some of this concern is realistic, some of it is not. Yet it is important that opportunities be given them to receive expert advice with regard to genealogical and hereditary factors in their blindness.

In this age range we must seriously consider problems of family counseling and problems existing for blind parents of sighted children. At times this counseling may be available by generic organizations in the community. Yet the agency for the blind must be in a position to give advice to the generic agency, pointing out the specific problems involved and how to handle them.

In this age range, awareness must be had of blind persons who are institutionalized for one or another reason.

Here again integration must be a factor wherever possible. The blind person, for example, in a mental hospital must have an opportunity to take part in the normal pursuits of the patient group. For this to be achieved, agencies for the blind must be in a position to consult with mental hospital personnel.

As one moves up the age scale, job loss becomes a factor. Here again rehabilitation counseling of the greatest strength is needed. But here again, also, the question of financial security and often of direct aid is involved.

Through all his years peripatologists must be available, whether for the person who had become dependent on a spouse who has now died or the person moving into new circumstances and new places, to assist him once again to become mobile.

7. The Adult Losing Sight

As noted above, it is important that good regional rehabilitation centers be available for the person losing sight. It is not necessary that these be local in nature -- and the attempt to set up local rehabilitation centers can ultimately result in watering down the rehabilitation center program. As yet the demand for such centers is too small to call for their multiplication. When a local center is established without sufficient case load, the result often is that it begins to take persons who were not eligible under

the original rules and no longer gives true rehabilitation training.

The deaf blind -- whether those deaf at one time and now blinded or those blind before and now deafened -- have a special problem. For them two national centers will soon be available, and if the deafness is profound and the blindness total or near to it, no attempt should be made to handle the problem by merely local agencies working for blind persons or deaf persons.

It must be recognized that for some persons losing their sight as adults, attendance at a rehabilitation center will not be possible. For these a strong program of community mobility training must be available with expert peripatologists as the instructors.

Additionally these people will need good home teaching in blindness skills; they will need psychological and perhaps psychiatric consultation; in addition they will need excellent social case work for them and their families, together with rehabilitation counseling for their employers and themselves.

8. The Geriatric Blind Group

No community can consider that it is taking care of its blind population unless it is giving special attention to the geriatric group. It should be recognized that the blind population reverses the statistics of the general population. In the latter group the great numbers are found in infancy and

childhood, with a regular tapering off into old age. The blind group, on the other hand, consists of very few children and young adults. Its increase is constant from early years, but it begins to swell above the age of 35, showing marked increase in the area of 50, and its greatest numbers from 60 years of age on, tapering off suddenly only at the years above 90. It is a conservative though a startling estimate that over fifty per cent of blind persons are in the age group above 65.

The White House Conference on Aging considered all those beyond age 45, and perhaps this would mark a convenient point for this report.

From 45 to 60 years of age, we will find a considerable amount of blindness resulting from diabetes and from glaucoma and the beginnings of blindness resulting from cataract, as well as blindness from other causes.

There seems no need for special treatment of those persons blind from birth who have now reached the 45-year mark. But the community must recognize that in this age group many will be found who had been successfully employed and who now begin to lose their employment, whether from automation or from other cause. These persons constitute a special problem in that their previous adjustment is disturbed. They may, therefore, need special assistance with regard to emotional problems and recreational problems and family problems --

and they most certainly will need assistance with regard to job or career and perhaps with regard to financial security.

Persons who always had sight and have lost it in this age group are for the most part physically capable of good rehabilitation center training. They should have every opportunity and encouragement to attend one of the regional rehabilitation centers of which we have spoken. With such training many of these people will be able to return to their former positions, and some of them to equivalent positions in business, industry or the professions. Here again rehabilitation counseling will be called for.

Since it is recognized that some of these individuals will not attend their regional rehabilitation centers, the same need as noted above exists -- for community mobility programs, home teaching, psychological and psychiatric consultation, and social case work. The problem of the recreation worker or the social case worker will be to encourage these persons by every possible means to return to those forms of recreation which were theirs before, or to equivalent forms in integrated groups -- thus keeping them from vegetating alone or in segregated groups of blind persons.

9. The Old Age Group

When we come to the group above 65, where more than fifty per cent of blindness lies, we must first recognize the

number of additional disabilities that will be found. In many cases these are simply disabilities of advancing years, some of them not necessarily severe in nature.

In other cases we will find all the problems of the senescent or senile blind and of the feeble, weakened body.

Here loss of hearing comes in with much higher incidence, and here physical problems often interfere with the achievement of good mobility.

Yet in this group is a strong core who are otherwise completely well or otherwise well for their age group, but whose normal activity is interfered with to a great degree by their blindness.

a. Housing

Housing is often mentioned as a primary problem. We take it first in order to give a negative view. In this view I believe strongly that there should be no special housing for elderly blind persons -- that is, no housing which segregates them as a blind group. We believe that the trend in the United States in recent years has been toward the closing rather than the opening of homes for blind persons, and we would not wish to see this trend reversed.

We are aware of the housing needs of the elderly population and strongly believe that these must be met. We further believe that blind persons in their advanced years should have equal opportunity to participate in such housing.

Our only commitment is that they should not be housed together as blind persons.

b. Medical Care

One cannot speak of the elderly population without speaking of the problems of medical care. We know that these must be solved and that rapid steps will have to be taken in the next few years. We do not, however, see anything special with regard to the establishment of medical services for blind persons.

c. Otological Care

This may seem contradictory since otology is a branch of medicine. We do feel that under whatever medical care bills are enacted by the federal government, opportunities should be made for blind persons to have special hearing attention, i.e., audiological tests and otological consultation. With this should be given for blind persons, as for all persons, an opportunity to receive necessary hearing aids from government sources. With blind persons, these should be prescribed according to their various specific needs. (We note that a lesser degree of hearing loss is more serious for a blind person than the degree that might be serious for the sighted one because of the inability to "speech read" -- that, on the other hand, the too early use of hearing aid may interfere with mobility and environmental cues for the person who is blind.)

d. Rehabilitation Training

It should be clear that some persons over 65 years of age can attend and benefit from the regional rehabilitation centers. But it is to be expected that their number is small.

At the present time, no such thing exists as a geriatric rehabilitation center for the blind. It is hoped that within the next decade beginnings will be made on the establishment of such centers. These, too, must be regional in nature, and it is not recommended that any community establish one until a basic framework has been built up for the rehabilitation course at such a center. It is, however, recognized that the community should anticipate such a development within another decade. Such centers would take newly blinded persons in the old age category, train them for a period of days, weeks or months, and thus prepare them to return to their own homes, to their own families, to their own small apartment, to their special geriatric apartment, to the nursing home, rest home, or convalescent home where they were living before.

In the absence of such rehabilitation centers, a strong concentrated effort must be given by rehabilitation agencies to the old age population among the blind.

The first focus of such training should be on peripatolgy -- on recognition of the environment, orientation in it, and a proper degree of mobility through it.

Emphasis then must be given to home skills and ordinary self care together with normal recreational pursuits at home. This will demand a corps of home teachers, expert in the geriatric area, and the furnishing of talking books, radios and various home devices.

Volunteer service for this group will consist for the most part of supervised volunteer visiting, with occasional reading as indicated by the needs of the person.

All such community services as meals on wheels must be available to blind persons in the old age category.

Other recommendations would call for the use of all techniques to keep the person from drifting into a world of senescence -- the establishment in nursing and rest homes of some sort of clock announcement of time and date and place. Above all, in nursing and rest homes, something must be done to interest the person in activity and to make him feel worthwhile.

This position paper cannot hope to solve geriatric problems which are not being solved for the general community. But it can strongly recommend that church and other groups make use of aged blind persons as of all aged persons for teaching the young and for other efforts which will bring them into contact with young people and make them feel their worth.

B. THE CECUTIENT

"Cecutient" is defined variously as "a state of defective vision", "a process of losing sight", and "a state of partial sightedness with or without probability of further loss of sight".

I introduce the term into this report not with any idea of making it standard terminology or of adding to the problems of nomenclature. Rather it is because our present terms -- "legal blindness", "partial sightedness", "industrial blindness", "educational blindness", "visual handicap", "visual deficiency", etc., etc. -- allow for such varied definitions and considerable confusion. For purposes of this report, "cecutiency" carries no implication of a progressive condition; it may be defined as "any degree of loss or absence of vision sufficient to interfere with normal activity (educational, economic, social, recreational) which would not be encompassed in our prior definition of blindness".

It is my intention that both terms be fluid; I have noted above that our definition of the "truly blind" would probably reach somewhere near 3/200 vision or 5/200 vision. "Cecutiency" then would cover an area from approximately 3/200 up to near normal vision.

As we discuss the problems of cecutiency in all its phases, it will be impossible to make a strict differentiation between those which should be treated by agencies or facilities

for blind persons and those which should not. In general it is our thinking that in our society labelling as "blind" introduces a social stigma, traumatizes the individual (or, in case of children, the parents) and those closely connected with him or them. We, therefore, believe that no cecutient person should be labelled "blind" and further that no agency which in its title and/or statement of purpose limits itself to dealing with the "blind" should be given responsibility for dealing with this individual unless the particular circumstances of the case demand it. It would undoubtedly be helpful to a community survey group if we could draw these lines rigidly; unfortunately, that is not possible. There will be instances where one cecutient child can be assisted without any reference to an agency for the blind, whereas another cecutient child with the same degree of vision must call on the services of such an agency. The same remains true of cecutient persons at all stages of life. The generic rule can only be that the term "blindness" and the use of the agency for "the blind" be avoided except where the circumstances of the case show that the total interests of the individual will be better served thereby.

It should be noted that whereas the field of blindness normally limits its interest to those whose vision "in the better eye" is below a certain amount, it is important

in considering cecutiency to include those whose better eye is completely normal if the individual's visual capacity is limited because of problems in the other eye.

1. The Child Born Cecutient

It is impossible to obtain statistical information in this area. We can find material concerning the more gross problems -- but we are not yet certain about the slight deviation from the norm since we cannot yet know what the norm is when we are treating of the early pre-school child.

The position paper on prevention of disability will undoubtedly refer to pre-school screening; we cannot, however, entirely overlook this point here. Pediatric hospitals in the community should certainly be aware of any work which is being done with the screening of infants' vision; at this point their entrance into this field might only be for purposes of building up statistics or discovering a norm. In the near future it is probable that this form of screening may take on new importance for the early discovery of eye abnormalities which can be corrected, and can then proceed to planning for their correction.

When the existence of eye abnormality is discovered in the child, good counseling must be available to the parents. They must be made aware of the perceptual difficulties which may result and even the social difficulties resulting for the pre-school child. Particularly, they must

be assisted to understand and accept the prognosis, whether it be a static one, a likelihood of improvement, or one of progressive degeneration. They must be further taught the difficulty, almost the impossibility, of interpretation of the condition. (Although the normally sighted individual has difficulty in recognizing the problems of total blindness, he may to some degree understand the reality aspects by his own experience blindfolded, but he has no way of simulating the problems of cecutieny.) The parent must recognize that, though the eye condition itself is static, various physical factors in the environment such as light and contrast may vary from day to day or moment to moment, thus changing the ability of the child to see what is around him at a particular time.

Counseling is particularly called for with regard to the recreation and intergroup experiences of the pre-school cecutient child. There will be times when the parent, acting on his own feelings or on ophthalmological advice, will so overprotect the child from eye damage as to warp his self-image and destroy his capacity for good interpersonal relations. The working out of any balance is extremely difficult and most demanding of parents and counselors.

In treating of the pre-school blind child, we have recommended the possibility of some experience in

parents' groups. In speaking of the pre-school cecutient child, I feel it unrealistic to hope for the establishment of such groups. Nor do we believe that there is the same need for psychiatric consultation; we strongly feel, however, that psychiatric consultation should be available in those cases where the counselor believes it essential.

In those cases where there is a combination of cecutiency and brain damage, we know of no available program. (We ourselves are watching with interest, but without arriving at any conclusion, the work of Doman and Delacato on brain damage and visual difficulty at the rehabilitation center in Philadelphia.)

We strongly recommend that in every instance of visual deficiency a complete audiological examination be given and otological consultation be available.

a. Nursery School and Kindergarten

For the cecutient child at nursery school age educational consultation becomes necessary. As with the blind child, so with the cecutient child: he should attend nursery school with normally sighted children. Here it becomes essential that the teacher be given assistance to understand his problem completely. In those rare instances where ophthalmologists feel that some damage will be done by "too much use" of the eyes, the teacher should be aware

of it. In all other instances the teacher should be made aware of the fact that the ophthalmologist recommends complete use of the eyes. The counselor or pre-school consultant should have all facts available with regard to eye use or indications concerning participation in active recreation, and should be able to interpret these fully to the teacher.

All that has been said about nursery school may be applied to the kindergarten.

Like the blind child, the cecutient child may acquire certain postural or other difficulties marking him as different. These may come from many causes; among others, the fact that the child turns his head so that a clear portion of visual field may see the light, or turns his head in order to avoid the light. These problems too must be interpreted to the teacher together with any means of overcoming them. (Without such interpretation the average teacher may be inclined to make a frontal attack on the problem and thus fix and focus it more deeply, making its later correction the more difficult)

In the present state of our knowledge regarding mobility training for blind children, we are unable to delineate the exact degree of visual loss or visual disability calling for such training. We cannot even say with certitude when the cane is called for or when there is a question of training the remaining senses.

In view of the increased use of blindfolding techniques or occluding for adults who become cecutient, it is perhaps necessary to include here a warning against using such techniques for the child who was born with limited vision. (The theory of using occlusion for adults who were adventitiously "blinded" and have now lost a large degree of vision is that without occlusion such persons will concentrate so thoroughly on the small degree of remaining vision as to interfere with the training of the remaining senses. On the other hand, the child born with a small degree of vision theoretically will have integrated this small degree with information coming from his other senses; to occlude such vision would, therefore, be interference and impediment to his learning.)

For purposes of emphasis, we repeat the need of audiological and otological examinations.

2. The Child Who Becomes Cecutient from Birth to Five Years of Age

Again we are without statistical information; we do not know how many children born with full sight become cecutient before the age of five. Experience would indicate that the number is small. We suggest that in those instances where this happens the child suffers many of the same problems as does the adult under similar circumstances. Here

again the trained counselor is called for -- but his actions must be dictated by the particular circumstances of the case.

3. The Cecutient Child in Grammar School

In the first quarter of this century ophthalmologists, together with organizations for the prevention of blindness, waged a campaign for the establishment of "sight saving" classes throughout this country. The action was predicated on the strong belief of ophthalmology that "too much use" of sight would cause its deterioration and ultimate loss. Today ophthalmology is taking an entirely different viewpoint with few exceptions; it now appears that ophthalmologists are saying that in most cases of visual difficulty the eyes may be used as much as they are capable of and that there will be no resultant visual damage. YET THERE ARE SOME CASES OF CECUTIENCY WHERE SOME OPHTHALMOLOGISTS WOULD RECOMMEND THAT USE OF VISION BE LIMITED AND MANY CASES WHERE A FEW OPHTHALMOLOGISTS WILL PRESCRIBE SUCH LIMITATION.

Generally we believe that the day of "sight saving" classes is passed. Yet there remains the problem of the educational care of the child who is unable to read ordinary print or unable to see the blackboard. This problem is solved in different ways. As in the case of the blind child, there are the probabilities of (a) the residential school, (b) the

classroom in which the cecutient child remains, (c) the resource room, and (d) the itinerant teacher. Recognizing that each case must be solved to some degree on an individual basis, we strongly recommend the use of the itinerant teacher program where practicable.

There is a wide difference of opinion among educators as to the degree of visual deficiency which demands the teaching of braille (cf. Study by John Walker Jones, "Blind Children -- Degree of Vision, Mode of Reading: An Analysis of Children Registered with the American Printing House for the Blind in January 1960", U. S. Government Printing Office, Washington, D. C., 1961.) There is so little agreement on this that no one writing a position paper can give any community clear norms in this regard. What is demanded is competent educational consultation to keep abreast of the latest thought and to apply it to the problems of the particular child.

Similarly, there is disagreement with regard to the amount of clear type or large print which should be used as opposed to the use of devices for magnification. (Sometimes the "opposition" exists only in the minds of those dealing with the children, and a good combination of both may be achieved.)

Although it will come more clearly into the purview of the paper on Prevention of Blindness and Restoration of Sight, it is perhaps necessary that we underline here the

importance of low vision clinics and their optimum use. It is only within the last two decades that such clinics have begun to get proper recognition. Even today there are excellent and even outstanding ophthalmologists who have little experience with the prescription of low vision aids. For the cecutient child or adult, it is essential that the community furnish opportunity for examination by those who have specialized in the fitting of magnification and telescopic devices to improve low vision and, further, for continued treatment by those whose experience and training have prepared them to assist in the use of such devices. The community has a further obligation to furnish financial aid for the purchase of prescribed devices where their purchase would be difficult for the parents. (Whether, beyond this, there should be elimination of a means test in these situations is a question which must be decided by the community itself.)

Although we have included this section about low vision under our heading, "The Cecutient Child in Grammar School", it has equal application to the cecutient person in all stages of life.

We recognize that agencies for the blind have given great stimulus to low vision clinics in this country, particularly under the aegis of the Vocational Rehabilitation Administration in the Department of Health, Education and Welfare. While we respect and salute their activity, it is our strong

opinion that this is primarily a public health function, an obligation of the community, and one that should be centered in eye hospitals or eye clinics. Unless the agencies for the blind are sure that that obligation will be fulfilled by the community, we feel they cannot let down in their own activity in this area.

In the school program, as with the blind child, there is need for (a) consultation for parents, (b) strong opportunity for recreation, for physical education, for physical sports, and for hobby activities, (c) for mobility training where it is indicated, (d) for enrichment opportunities, (e) for counseling on social problems, and (f) for vacation time counseling to be sure of the development of interpersonal relations.

As for the child of normal vision who becomes cecutient during his grammar school years, we repeat our recommendation made in the section on Blindness. It becomes necessary that (a) special counselors be deeply involved in his life, or (b) if the cecutiency is of extreme severity, that he be sent to a residential school for at least a period of a year. It is our opinion that the latter is extremely traumatic. We would recommend it only as a last resort. Instead we would call on psychological consultants, peripatologists, and home teachers to work closely with the parents as well as with the child in developing his skills and returning him to his local school.

4. The Cecutient Child of High School Years

Special problems enter the life of the cecutient child of high school years. If he has been unable to read regular size print, it probably has been quite possible to furnish him with large print textbooks in earlier years; at about high school time the reading demands are so great that it is inconceivable that all of these can be cared for with large print.

As recreation for the high school boy becomes more organized and often takes the form of interschool sports, he may find himself ruled out. The boy or girl of high school age whose visual deficiency is a visible one may, whether from internal or external factors, find himself not attractive or not acceptable to the other sex at a time when this becomes of importance. Part-time job opportunities begin to have a place in life at this stage, and the cecutient high school boy or girl may find these greatly limited. The impossibility of driving a car, which is such an important status symbol for him at this growing stage, may be suddenly severely traumatic. The opportunities for a vocation and life goal may be so limited as to be seriously upsetting at this time. Even the fact that the cecutient student is likely not to be drafted may seem to him a deprivation and a mark of abnormality.

One internationally known psychiatrist has referred to this period of life as one where "abnormalities are normal"

and again as a time of multifold neurotic states. The statement, admittedly strong and intended to convey the difficulties of adjustment in adolescence, certainly brings out some of the churning difficulties which mark this period of life. If to any extent this is true for the normal child, then certainly great are the problems of the cecutient child with the added reality situations which we have noted. It is not then out of place to call for the strongest professional assistance in this time.

Even in the most restricted concept of education, it is necessary that the cecutient high school student (or the cecutient child entering high school) have the direct assistance of an educational counselor. Resources must be available for the student unable to read ordinary print which will enable him to do his reading by other means: talking books and tape recordings must be made available, and the community must in some fashion furnish reader service sufficient for his needs.

a. Consultations

The educational consultant must be prepared to work with the student in choosing courses (academic, business or trade) fitted to his abilities, his personality, his aspirations, and future reality.

b. Vocational Guidance

Competent vocational guidance must enter strongly

during high school years. The process cannot, however, be limited to this. It is essential that recreational and personal guidance be given to him and that there be available competent counseling at whatever level is demanded for his psychological growth. Additionally, the peripatologist must be available to see that what has been taught him before is being put to good use and that further training be given if necessary.

Dropouts must again be considered. It is hoped that proper counseling can minimize this problem, but it must be expected that even with such counseling some will drop out. Now psychological counseling as well as vocational counseling becomes of great importance. Otherwise there is strong likelihood of delinquency or permanent maladjustment.

Before leaving the high school age group, we should give some consideration to those who become cecutient during this period. Here we can also say that if the cecutiency is sufficiently severe, the mature cecutient student should have an opportunity for training at some rehabilitation center which is not job oriented but is rather oriented towards psychological and skill adjustment such as will allow the student to return to his high school career and whatever may follow it. Where the cecutiency is less severe (as, for example, the student losing one eye in an accident but with the other perfectly normal, or the student who suddenly finds himself with

a reading loss but capable of most other activities), then we feel it important that the community furnish such psychological counseling as will enable him to understand and cope with his own feelings, together with any vocational counseling necessary because of a reorientation of goals.

5. Post High School Years

For the cecutient young person rehabilitation counseling, job counseling generally, and generic social counseling should be available.

There may also be further problems of mobility to be considered by the peripatologist.

If the student is going on to college, it may be that some consultation should be given to college counselors in order that a complete understanding of the individual's visual condition be assured. For some students at college level, reader service, taping service, etc., will be essential.

As for those becoming cecutient immediately after high school, the course indicated will be dependent upon the degree of disability. If it is not too severe, it may well be that only some personal counseling and guidance is called for. If more severe, then all the resources we have considered above should be brought to play -- and if feasible the young person should attend a rehabilitation center. Here again we must express a strong caveat -- under no circumstances

should the onset of cecutiency be taken as an indication for sheltered workshop training. Other factors may demand this, but cecutiency itself cannot -- and any inclusion with blind persons in a sheltered training situation could well be permanently traumatic.

6. The Cecutient Adult

For many persons reaching adult years after a life of cecutiency, no special services will be demanded. These persons will take their regular place in community life without any need for such services, and in fact any aggressive carrying of such services to the individual might force him to a life of dependence, or might upset his community relations.

We must recognize that for others in this broad range of visual difficulty, services will be necessary. Job placement services will be important for some. We believe that normally such services can be taken care of by specialists in the vocational rehabilitation agency of the state; but it is the obligation of the community to see that competent services of this kind are available (not simply services geared to totally blind or services which would stereotype job opportunities for cecutient persons.) For the most part we see such services as existing in generic agencies rather than in an agency whose outlook is geared towards blind persons.

With the cecutient group, as with any normal sighted group, there will be marginal persons incapable of taking their part in normal life. We believe that the treatment of

these persons should be geared not primarily to their cecutiency but rather to those other factors which make them marginal (whether these be low intelligence, personality factors, lack of motivation, or whatever they may be.)

Financial security must receive some special treatment here. Under existing law, persons having less than 20/200 vision in the better eye or an equivalent loss of field are under certain circumstances eligible for assistance under the Aid to the Needy Blind section of the Federal Security Law. Following too rigidly our definition of cecutiency, some might be inclined to work for the elimination of many of these persons from such benefits. This would be entirely contrary to our own opinion. For purposes of eligibility for aid, we could well see the present definition of "blindness" broadened rather than restricted.

To explain further our feelings in this regard, we would make it clear that cecutiency in itself can be a severe disability with regard to job placement and job opportunity. It is also our philosophy that lack of financial security rather than acting as a motivation to people, acts as a hindrance to their adjustment and their readiness to take on employment. Our own desire in this regard is that persons with severe cecutiency not be labeled as blind except in those cases or conditions where the general public would

believe such a term truly applicable. We feel that labeling them under other conditions does definite harm to the individual and to his place in society.

Financial aid then should be available -- but it should not force the person into relationships with an organization or agency "for the blind". We therefore repeat with regard to the cecutient what we said of those who are blind: "All laws, therefore, which have to do with financial aid to needy (cecutient) persons should be reviewed to see that they offer a substantial floor of financial security so that the (cecutient) person will not be made neurotic by worries about his ability to live in some degree of ease and lack of worry."

We refer again to what we have said previously about deafness or profound hearing loss and the need for proper audiological and otological services.

We further refer to what we have said above concerning the possibility of hereditary factors and the need to receive expert advice.

Particularly in situations where the social visibility factor is high in hereditary cecutiency (e.g., albinism), family counseling may be important for parents and children.

Surveys of persons institutionalized in mental hospitals and elsewhere are important to discover cecutient patients who need special understanding and opportunities

to take part in the institutional situation or to be released from it.

In days of automation and other change in economic factors, some attention must be given to the cecutient adult who after years of holding one position loses it and finds restricted job opportunities -- a problem concerning rehabilitation counseling and also the question of financial security.

With the adult as well peripatology may be called into play -- particularly because of changed circumstances of living and possibly because of some decrease in vision.

As for the adult becoming cecutient, most of what we have said in other sections seems applicable here without further direct consideration.

7. The Geriatric Cecutient Group

Now we are entering an age in which something like cecutiency is "normal". That is to say that horns are certainly different for the group 45 years of age and up.

A person who has always had a severe visual loss reaching the age of 45 in our civilization begins to find new problems -- most of them concerned with job and economic opportunities.

It seems unnecessary that we add anything here to what we have said with regard to the blind group at this age or the cecutient group at other age levels.

Undoubtedly the position paper having to do with Prevention of Blindness and Restoration of Sight will give serious consideration to visual screening, visual care, etc., for this group.

In considering those who become cecutient from 45 to 65 years of age, the resources demanded are very much those previously outlined: if cecutiency is severe, the rehabilitation center; if less severe, then the assistance of community competence.

8. The Old Age Group

In the years over 65, we come to the time of great sensory deficit. The person therefore who has been cecutient all his life may now be disturbed by impairment of other senses, particularly of hearing. Here again audiological and otological factors demand proper screening and care. The peripatologist may again be called in to interpret the losses in the other senses and to assist the person with mobility problems caused by such losses.

Often the social stigma of cecutiency now declines because of the amount of visual loss in the peer group.* This must not be taken for granted, and the possibility that such stigma still exists must be considered in geriatric care.

*It is of interest to consider that for one cecutient group which we have mentioned, those with albinism, the social visibility factor diminishes markedly with age -- the skin and hair coloration of the albino remain the same, but age makes those of the non-albino approximate it to a degree where often he no longer stands out.

What we have said above for blind persons in this age group remains true for the cecutient with regard to housing, recreation, medical care, volunteer services, and so on.

As for the person becoming cecutient after 65 years of age, our society knows no special training for him but should be prepared for the development of some rehabilitation training in future years in cases where the cecutiency is severe.

SUMMARY

We have attempted to consider in the broadest terms "true blindness" and "cecutiency" at all stages. Necessarily we have talked in terms of patterns and often have lost sight of individual problems.

In general our attempt has been to distinguish between those whose degree of visual loss is so great that the public would consider them "blind" without stretching the imagination, and those others who, while not fitting this category, have so severe a visual loss as to interfere with opportunities for normal living.

Our recommendations have been based on the principle that the "non-blind" group must be treated in different fashion from the "blind" group or harm will be done to both;

we have even suggested that in many instances the groups must not be treated by the same agency. Undoubtedly in the application of this principle, what we have spoken of as fluidity must at times seem extremely rigid. We are aware that in any services of community planning, it is not always possible to remain with pure theory or with that which is ideal, yet we believe that the attempt to follow our guide lines will in the long run mean better services to both the "truly blind" and the "cecutient".

As for statistical information necessary for any good planning, we must point out that the most widely respected national agency for the blind gives a variation in the number of blind persons in the country ranging from 380,000 to 960,000. It is obvious, therefore, that no truly reliable statistical information is available. If this is true, as we believe, for the generic group under our present definition of blindness, it is impossible to find a reliable basis for statistical planning when one brings forth new definitions such as we have elaborated here.

The forthcoming survey by Western Reserve University, using a consultant borrowed from the American Foundation for the Blind, will undoubtedly be of great practical value to the planners in the Cleveland Health Survey group.

This consultant will work with the Health Survey members in any attempt to project statistical information.

or to make broad estimates, but there will be no attempt made in this report to give statistical information since the very attempt might throw off any planning efforts.

C. COMMUNITY RESOURCES INDICATED

Community resources demand that the proper care of the 1 in 50 persons in Greater Cleveland having a severe visual handicap, including the 1 per 1000 "truly blind", demands on the part of generic agencies in the community a lack of prejudice, an interest, knowledge and information, and the ability to work in cooperation and coordination with special agencies for the visually handicapped, as well, of course, as with hospitals and general health facilities. It also demands the existence of certain specialized agencies for the visually handicapped, some of which will be public by necessity, others public or private according to the philosophy which informs social work in the area, according to the choice of the citizenry.

Of the services listed below, some few can be furnished by a generic agency and some must be so furnished, some perhaps by agencies for disabilities not specifically or solely concerned with visually handicapped, and still others can only be furnished by an agency whose specific interest and expertise concerns the visually handicapped. We do not feel that it is fitting that a position paper

author from outside the Cleveland area should attempt to make recommendations with regard to the housing of these services unless there is specific and strong reason for it.

For the care of children from birth through adolescence, resources must be available which can assist the family of the visually handicapped child. There must be true expertise in the development of the visually handicapped child and also in the education of such a child; this expertise must be aggressively brought to the families of the visually handicapped children from the time of their infancy.

In the field of education, both residential schooling and opportunities for schooling in the regular public or parochial schools must be available both to the truly blind and to the cecutient child. Along with these opportunities there must be "neutral" counseling available to assist the child and his parents in the choice of educational facilities. Additionally, there must be educational opportunities for visually handicapped children who have other disabilities, physical, mental or emotional, and the counseling service must be aware of them and adept in using them.

Financial aid must be forthcoming for these schools and for those educated in them: to see that the teaching is of

the highest quality, to furnish transportation, to ensure sufficient reading, to purchase an optimum number and range of supplementary items, and to be prepared for the granting of scholarships at the college level.

The resources in peripatology must exist from pre-school years through the geriatric age. As indicated this will demand trained personnel, not only in rehabilitation centers but in every part of the community and in any special schools or regular schools which blind children may be attending. Such services should also be available to adults institutionalized in mental hospitals or elsewhere.

In the school years, opportunities must be given for proper psychological testing, guidance of all kinds, vocational training at its best, for recreational and social counseling and training, and for college aid. Special attention must be given to post school counseling, whether with dropouts or with high school graduates not continuing.

There must be special rehabilitation opportunities. We strongly recommend that sufficient funds be available to send persons outside the state to regional rehabilitation centers offering total rehabilitation to those who are newly blind. We think that the community should be on record against using job oriented rehabilitation centers in cases where total rehabilitation is called for, but the community

must be prepared to subsidize job training and personnel training as demanded. Planners should watch closely the development of home teaching (the first post-graduate course for home teachers of the blind has been established only within the last year) and should make sure that home teaching (1) includes the best rehabilitation efforts, and (2) does not inhibit the blind person from securing total rehabilitation where it is indicated. Vocational counselors specializing in work with the visually handicapped should be of the highest professional caliber and numerous enough to keep up with the many problems involved. Rehabilitation counseling personnel should include those expert in assisting with placement not only in the manual labor or factory field, but also in areas of horticulture and agriculture, and also should be able to give concentrated assistance to white collar placement.

It is essential if prejudice is to be overcome that some agencies have the responsibility for public education concerning visual handicaps, including the handicap of blindness.

Agencies must be in a position to offer financial assistance and must receive strong community backing to make certain that this financial assistance is distinctly a substantial floor and not a pittance which increases anxiety; we have reference not to the traditional financial supplementation but to the granting of aid to the blind

under the Federal Security Act. It is our feeling that any planning committee for the Cleveland area should review the financial plan of the state agency in order to ascertain that such financial assistance is optimum.

Prompt and efficient service must be given with regard to the distribution of talking book machines and talking books and their prompt and adequate repair and replacement. Opportunities for special braille books, taped recordings, and embossed disks must also be available. Additionally, some agencies should coordinate reader service especially for college and university students, and for professional persons; although much work can be done by a well organized and coordinated volunteer service. Greater independence can be given to the blind person when a state agency can pay for such a service.

A voluntary agency should oversee the coordination of guide service and general volunteer service where such is necessary for individual blind persons.

One or another agency must have responsibility for such necessary things as seeing to it that visually handicapped persons have adequate housing, that low vision clinics are established and available, that workers for the visually handicapped are constantly alerted to the opportunities for sight restoration, and that audiological

and otological services are furnished as a matter of course to all persons in the range of severe visual handicap.

It is almost essential that those agencies who see their aim as working for the support of blind people rather than the rehabilitation must have the very best of social case work services which will never lose sight of their rehabilitation possibilities.

Since many visually handicapped persons will have one or another additional reason for being classified in the "marginal" group, there must exist opportunities for training such marginal persons for employment. The community must reach some consensus with regard to sheltered shops and their necessity, and must make a determination as to whether or not to support such workshops and whether or not to move into some home industry programs; it must take under consideration the question of whether to include visually handicapped persons in generic sheltered shops or to establish and support sheltered workshops specifically for those with a visual handicap. The problem of establishing activity programs for marginal blind persons without segregating them from those with normal sight must be considered as must the existence of any segregated program for its harmful influence on those concerned and on the general public.

The Greater Cleveland community should be aware of regional programs for the deaf-blind, and should be prepared to make proper referrals to these programs and to give special service to deaf-blind persons who have received training.

For the geriatric group, emphasis on peripatology and home teaching must be renewed, and additionally there must be a community drive to integrate elderly visually handicapped persons into whatever programs are operative or indicated for the elderly of the area. This will demand action of social workers with the elderly visually handicapped, with those operating programs for the elderly, and often with elderly persons who are not visually handicapped, so that they will accept and assist the others.

A program must be established, if one is not existing, which will visit and evaluate rest homes, nursing homes, and the like, for their ability to care for their visually handicapped clients, and then will proceed to give proper training to the personnel of such homes.

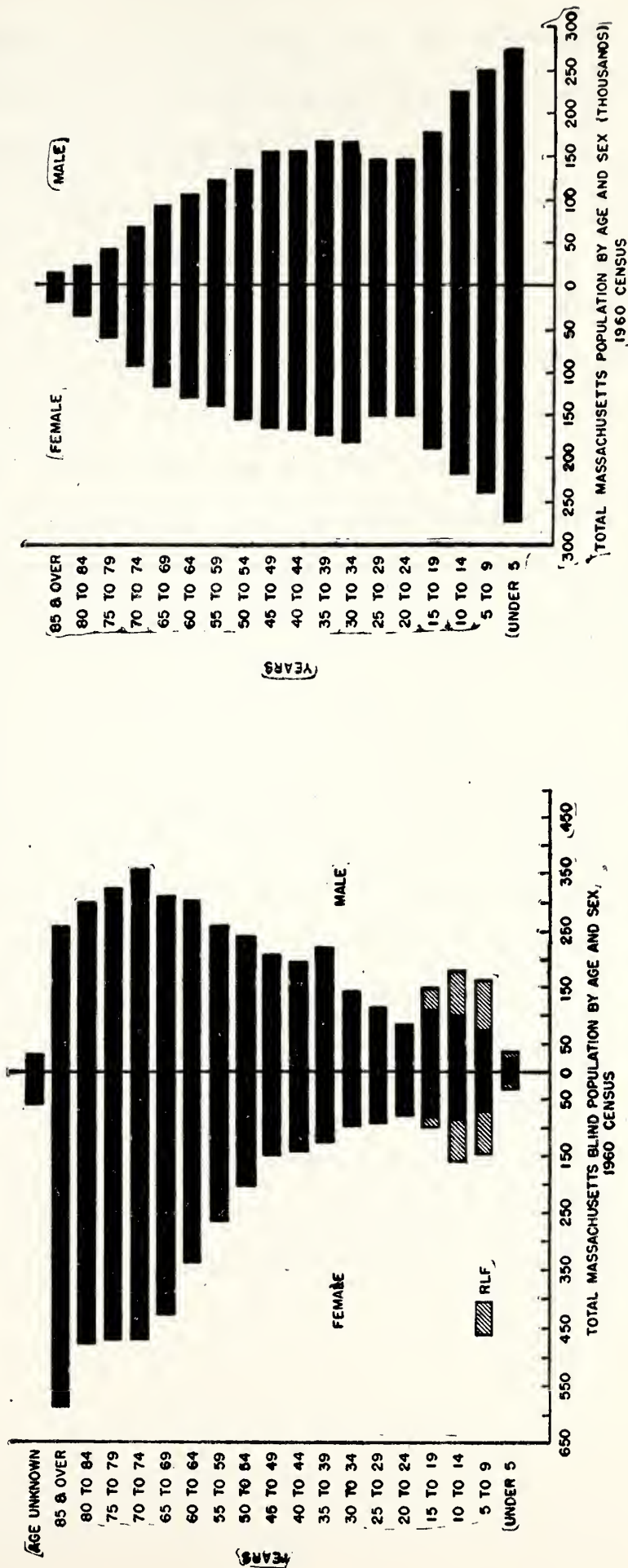
Most communities now concerned with the elderly are paying special attention to diets of older persons; any planning for Greater Cleveland must note that this becomes particularly important to those who are visually handicapped, whether because they are less able to prepare their own food,

or because they are less able visually to appreciate food which is prepared for them.

Older persons, visually handicapped, will not properly be served until and unless consultants on the problems of the visually handicapped are jointly and regularly working with all agencies in the community which are concerned with the care of those in the geriatric group.

The author recognizes that the above outline of resources is vague and without specific application to the needs of the Cleveland community in conjunction with already existing resources. The list has been purposely done this way, since no attempt could be made to evaluate existing resources and also since the community's own philosophy must be brought to bear on decisions with regard to the establishment of any new resources.

A. GRAPHIC CHARTS



AGING IN OUR TIME — Effects of greatly increased longevity are shown in the above diagram based on 1960 Massachusetts population figures. The general population chart (in thousands) at the right indicates numbers at different age levels, graphically presenting the number of older persons in our population. The chart at the left shows the Massachusetts blind population in the same year. It brings out with clarity the heavy percentage of older people who are blind. Shadowed areas on the chart denote those whose blindness was caused by retrolental fibroplasia. (Copies of the charts are available at cost—on glossy paper—from the LISTEN editorial office.)

Although the charts shown are for Massachusetts, they should be helpful for the Greater Cleveland area.

1. Discussion of Contrast

The contrast in age distribution between the total population and the blind population is clear, but a few points might be helpful for study. Beginning at the 50 to 54 level, it will be seen that the total population is already decreasing, whereas the blind population is increasing markedly. Now if it is recognized that in this 50 to 54 group there is a percentage (how large we cannot say) whose blindness is the result of a disease state which would shorten life, as for example those blinded by diabetes, we should look for a sharp decrease in the number of blind persons above this age group. In the 55 to 59 group, we are already getting a goodly percentage of blind persons (again we must be vague) who are undergoing serious vascular and arterial changes; here again we would expect a severely limited life expectancy. One would therefore foresee a further limitation in the numbers above this point.

When one reaches the 65 to 69 blind group and thinks of the mobility limitation, one would expect that metabolic changes, increase of disease osteoporosis, and other factors would cut further the expected life span. Here, too, one thinks of the loss of "will to live" from

persons losing sight in this group.

Yet, with all that, the charts show a marked increase .

2. Retrolental Fibroplasia

The chart showing the blind population shows the retrolental fibroplasia group as shaded (or cross-hatched). If this had not been done, the picture would have been seriously skewed.

This group represents those blinded during the scourge of retrolental fibroplasia. This was the group consisting mostly of premature infants weighing less than three pounds at birth whose blindness was later discovered to be the result of high concentration of oxygen in the incubator. The condition was first discovered and named in the early forties. Its major cause was discovered and eliminated in the fifties. It is likely that there will continue to be children blinded by retrolental fibroplasia, but their number will be very small indeed compared with the numbers during the "scourge".

There will remain for many years on statistical displays concerning blindness what is sometimes referred to as the "retrolental bulge". Statistically the term has meaning as representing a distortion of distribution and of projection. Humanly, it of course represents the suffering of many parents and the deprivation of many children.

In any planning for services for the blind, the "bulge" must be seen moving up the chart at five-year intervals. Thus, whereas the bulk of persons blinded by retrolental fibroplasia was in 1960 between the ages of 5 and 14, in 1970 the majority of them will be young adults. In 1985, this group will have moved up toward what is now conceived of as the top age bracket in the new employment group (45 years).

We regret that exact figures are impossible, but there is reason to believe that some children affected by retrolental fibroplasia during the "scourge years" but not blinded at that time, will come into the category of legal blindness or even total blindness as the years go on.

3. The "Hidden Blind"

Those reading the pilot study made in Cleveland by the American Foundation for the Blind will note the reference to the "hidden blind".

Without research, and simply operating from "experiential hunch", some of us have long believed that in the Massachusetts figures our poorest reporting of blindness was in the upper age brackets. Thus, we have suspected that, in the age group 65 to 69, a number of people lose sight and are never reported to agencies for the blind. We have suspected that this figure increases with age, and that in the years

over 85 the percentage of blind persons not reported is large indeed. The Cleveland pilot study would seem to bear out our hunch. To the extent that this true, the chart of the blind population is not fully representative above the age of 65; if it were so, then the contrast between this graph and that for the total population would be even sharper.

4. Turnover

Planners must be aware of the rapid turnover in any list of blind persons, especially in the upper age brackets. Entrance onto a register of blind persons may be followed very rapidly by exit from that list.

An illustration may be helpful. The Biometrics Branch of the National Institute of Neurological Diseases and Blindness made a study of the registry of the Massachusetts Division of the Blind to obtain information concerning persons first registered as blind between January 1, 1940, and December 31, 1959. Data were obtained on 11,000 persons registered in that period, and it was discovered that 550 of these had been taken off the list by December 31, 1961, because of sight restoration. By the same date, 5,200 had been removed by death, whereas 750 were not located.

In the meantime, it can be presumed that these 6,500 were replaced by at least 6,500 others.

Hypotheses and conclusions which may be arrived at

from such statistics are both too tenuous and too numerous to be discussed in a report of this kind. They should, however, be a basis for discussion when the author of the position paper meets with the planners.

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